Somebody I Used to Know

by Wendy Mitchell with Anna Wharton

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You could be forgiven for thinking from the first italicised page of Wendy Mitchell's memoir *Somebody I Used to Know* that she is addressing a dead partner or relative. Mitchell describes a momentary feeling of total blankness,

A
big
dark
black
hole

and the passage ends '*And the worse thing was, just when I needed you most, you were gone*' (p.1). Yet as these second-person flashbacks continue through the book it becomes clear that, rather than anybody else, the you she is writing to is her past self, somebody who was defined by her achievements and active lifestyle, somebody she used to know but who is now very distant from her.

Despite this irrevocable rift between old and dementia selves, Mitchell's book, written in collaboration with ghostwriter Anna Wharton, has already become a bestseller and my copy is from the fifth print run since its publication at the beginning of February 2018. Its appeal is clear: Mitchell writes to us from the other side of dementia, documenting how the disease subtly undermines her agency but also demonstrating her own open-minded and frequently optimistic outlook on a disease which is so often just shorthand for dreaded old age and senility. Mitchell has young onset Alzheimer's and her book sets out to prove that 'dementia has a beginning and a middle, as well as an end' (p.140). Alongside flashbacks to her past self, it documents her illness from its beginning as unexplained falls while jogging through her dealings with clinicians uninterested in her after diagnosis, going on to depict her struggle to continue working and subsequent reinvention after early retirement as a successful blogger and an ambassador for better research and public understanding of the disease.

The book shares several tropes and set-pieces we might expect from a dementia narrative – the secret trail of Post-It reminders, the lost words during a public speech, the breaking of the diagnosis to horrified children, the reluctant self-extraction from a high-powered job, the regaining of control over the disease through a public advocacy role – and juxtaposes Mitchell's advancing dementia, which we might understand as one of a loss of autonomy, with the hard-won autonomy of a resourceful woman who brought up two daughters on her own and progressed from working as a cleaner to become a roster 'guru' leading a non-clinical team within the NHS (p.81). Like those before it, Mitchell's narrative contributes to several ongoing discussions about how society deals with dementia, such as the way doctors relate to newly

diagnosed patients, the difficulties of retaining independence, and the problems around assisted dying and advanced directives for people whose capacity to make decisions is eroded so gradually.

However, it has something which that other dementia bestseller, Lisa Genova' *Still Alice*, does not. While Genova's fictional world gives an uneasy sense that (god, forbid!) even rich white academics get dementia and so can be read as a narrative in which the disease is almost recompense for a privileged lifestyle of mimosas on Harvard Square, *Somebody I Used to Know* makes the illness seem like something that can affect anyone irrespective of background, and, more importantly, something that can be accommodated in many respects through better awareness of how the disease affects people. Partly this is due to Mitchell's less privileged background, and because her book has what Anne Hunsaker Hawkins has called the 'experiential authority' of non-fiction illness autobiography which rivals the medical authority of medical professionals (like Genova, who is a neuroscientist) with the first-hand expertise of a patient (Hawkins, 1999). Yet it is mostly down to Mitchell's practical way of dealing with her disease and her repeated ability to persevere, and indeed to innovate, when times are tough.

Although never prescriptive, Mitchell details her own experience of difficulties presented by dementia alongside descriptions of how she has continued to live an independent and fulfilling life with the disease. Moreover, although there are moments of lyricism – Mitchell understands her dementia as a temporary fog or snowstorm that whites out her thinking and at one point Alzheimer's is figured as 'a thief in the night, stealing precious pictures from our life as we sleep' (p.71) – the book's prose is more often straightforward and to the point, rich instead in idiosyncratic details given in the first person by someone who, Mitchell is clear, is 'living with' rather than 'suffering' from a disease (p.173).

She extolls the adaptive benefits of modern technology and social media for someone whose memory or speech often let them down and stresses how minute forward planning allows her to travel to attend dementia conferences and workshops on her own. Some of Mitchell's observations are particularly valuable since they may be unfamiliar to general readers, such as heightened sensitivity to noise and bright colours, inability to deal with rapidly changing environments or to understand that cupboards and doors might have anything behind them. She also finds solace in experiences which are broadly thought to be negative: on believing she can see her parents again she writes that it is not unethical to go along with such a 'fantasy' because it is more important that you are 'valuing the person's experience' (p.193). She thus makes the important observation that, while the disease disrupts our memory, we are still able to find value and pleasure in experiences that take place in the moment. As she tells Julianne Moore, star of the film version of *Still Alice*, 'I live for the moment […] I just enjoy each day as it comes' (p.149).

While the book is valuable for presenting Mitchell's point of view, I would have liked to read a passage indicating the role Wharton played in producing the book. As a professional ghostwriter, she is given a small byline on the inside title page but not on the front cover and credited in Mitchell's acknowledgment as someone 'without whom this seed of an idea would never have grown' (p.299). On her website, Wharton offers a range of packages for would-be writers starting with basic marketing and promotion advice to the elite Bestseller package where she produces and publishes an entire book based on interviews with the 'author'. However, her previous successes appear to have been ones she sought out herself and are all first-hand accounts by women who have overcome situations of adversity, such as deafblindness, female genital mutilation or domestic violence. Elsewhere in interviews and a TedEx talk she sets herself up as someone with the skillset to empower women by providing them with the possibility of broadcasting their voice to a wider audience.

Presumably Wharton's role has been downplayed because much of the achievement of the text lies squarely with Mitchell and her existing blog; yet a section, however brief, on how and why Wharton approached Mitchell would be of interest. Moreover, if both authors were to address the mechanics of writing a memoir as, or with, someone whose memory is impaired and explain how far the clarity of the text relies on the

filter of Wharton's narrative expertise, it would make the process – which the authors agree elsewhere was collaborative – appear as less of a sleight-of-hand than it currently does, and provide a valuable insight for readers working on illness narratives or autobiography.

For purposes of science communication, I would also like Mitchell and Wharton to have distinguished more clearly between the dementias that Mitchell lives with – Alzheimer's and vascular dementias, which are associated with memory loss and slowness of cognition and movement – and frontotemporal dementia which is associated with more pronounced behavioural and personality changes and, as such, might be more difficult to map onto the positive sense of a continued identity that Mitchell advocates.

In all, this is a valuable and engaging contribution to mainstream literature on dementia and associated illnesses because it succeeds where Wharton has succeeded before, in demonstrating how it is possible to find a positive way of dealing with a difficult situation and getting a marginal voice heard by a general audience. Without being evangelical, it shows Mitchell repeatedly debunking the silent assumption that people with dementia are unable to make choices about their own life and gives an insight into how important small adaptations in understanding and technology can be for those who, as Mitchell emphasises, are still *living* with the disease.

Further Reading

Hawkins, A. H. 1999. *Reconstructing Illness: studies in pathography, second edition*, (West Lafayette: Purdue University Press).